Looking after HIV: Considering the needs of HIV positive looked after children

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Introduction

The Children and Young People HIV Network is involved in a wide range of activities relating to children and HIV and as a source of expertise in information, training and support. The need for this research was highlighted by cases brought to the network's attention by those seeking support to equip workers in this area and those who have witnessed poor or bad practice, and through the experiences voiced by young people themselves.

This publication considers the issue of HIV in relation to looked after children. It reflects the widespread research that has highlighted the particular vulnerabilities often experienced by looked after young people concerning their health and well-being; and considers how this relates to managing risk and HIV infection, as well as the care and support needs of those children and young people already diagnosed HIV positive.

The aims were to: consider the experiences of looked after children who are HIV positive; look at policy and practice guidance for looked after children and consider whether this is adequate to support professionals involved in the care of HIV positive children; offer recommendations for improving practice; and improve general awareness of the issues and risks faced by looked after children living with HIV.

We recommend that all professionals working with looked after children should consider the specialist needs of young people already diagnosed HIV positive and the risks presented to looked after young people of contracting HIV. In order to do so they will need to:

- address the policy and practice guidance within their organisations that relate to HIV

- consider staff knowledge and awareness around HIV – from transmission awareness to a more comprehensive understanding of the health and social impacts of HIV on young people's lives, identifying and understanding the impacts of stigma and discrimination – and assess the training needs within their organisations.

We also recommend that service providers should not wait until an HIV positive child or young person comes to their attention before addressing how equipped they are to meet their needs.

It is therefore important that an understanding of HIV and how it can be significant when considering the needs of looked after children is shared widely across children's services, rather than remaining a specialist area of knowledge and practice.

Terms and definitions

AIDS – acquired immune deficiency syndrome. The European definition of those with AIDS, covers all individuals who have one or more of the recognised AIDS defining illnesses.

Antiretroviral therapy – the general name given to the combinations of HIV drugs prescribed to HIV positive people.

CAMHS – Child and Adolescent Mental Health Service.

Children – people under 18 years of age

HIV – Human immunodeficiency virus

Looked after child/young person – a child/young person who is looked after by a local authority under the Children Act 1989. Includes children under care orders or who are provided with accommodation with no care order.

UASC – unaccompanied asylum seeking child

Young adults (as referred to in the data on sexual health) – those aged between 15 and 24.

Young people – those aged between 13 and 18

Methodology

Policies, practice guidance and previous research relating to looked after children and young people are consideredin order to illustrate the generic policy framework that informs the practice of those working in this field. This illustrates where generic children's policies may be inadequate to meet the needs of children living with HIV. It also highlights where there may be particular complications in adhering to specific areas of policy, illustrating that professionals and organisations may need additional guidance.

Initially, questionnaires were sent out to a wide range of organisations and professionals through national networks that cover residential units, foster care and social services departments. They asked for information about specific case examples of looked after children and young people living with HIV.

The questionnaires sought to discover the kinds of experiences professionals have had and where they faced challenges in meeting the needs of these young people within their organisations. They also sought to identify areas of good practice.

Very few questionnaires were returned. Various assumptions can be made about the low response. This is clearly a small group of young people and so we only expected a small response. But what became clear was a reluctance to discuss such cases, where professionals had been challenged by some of the issues an HIV diagnosis presents when caring for an HIV positive young person.

Despite assurances about the purposes of this research, many professionals did not want to discuss their case examples. Those who did agree to take part needed significant reassurance that they would be given anonymity in the publication. Being identified was a major concern both for the professionals and young people involved.

Consequently the evidence presented is based on a number of in-depth interviews undertaken with HIV positive, looked after young people. The young people interviewed were placed in foster care, residential care and semi-independent accommodation and one young person was detained in prison (not, at the time of interview, a looked after child but with a significant history of social services' support). The young people reflect two groups:

- those who were diagnosed before becoming looked after, having contracted HIV vertically, and as such had grown up living with HIV

- those diagnosed later in adolescence who were behaviourally infected with HIV.

Some of the key professionals in these young people's lives were also interviewed: residential care home managers, foster carers, social workers, senior managers and those from the voluntary sector.

These interviews offered significant insight into young people's experiences of being looked after and how their HIV status had affected that experience. They also provided an insight into the professionals experiences of being involved in looking after these children and young people, and highlighted some of the key challenges presented.

Additionally, a focus group was held at a looked after children's nurses' regional meeting to gain the perspectives of this group of health professionals; and the manager of a fostering service was interviewed for a more general understanding of fostering provision in relation to HIV.

There are four broad themes identified through the case examples:

- awareness and understanding about HIV
- confidentiality and information sharing
- stigma and discrimination
- managing risk.

Section 1 reflects the current situation regarding HIV and children and young people in the UK.

Section 2 offers an overview of current research concerning looked after children and current information concerning young people and sexual health.

Section 3 offers an overview of the generic children's policy framework that informs

practice and is relevant to this topic.
Section 4 begins to describe the research findings, reviewing the case examples of a looked after HIV positive young person and his social worker.

Section 5 considers the experience of a children's home looking after an HIV positive young person.

Section 6 considers the experiences of an unaccompanied asylum seeking child who was diagnosed HIV positive shortly after becoming looked after.

Section 7 considers foster care, with a policy and practice review and a case example reviewed.

Section 8 considers identifying and managing risk in relation to HIV infection, drawing on several cases.

Section 9 considers diagnosis of HIV during adolescence, looking at health and social impacts, drawing on a case example.

Section 10 brings together the research findings, offers some final conclusions and presents recommendations for practice.

1

Section One
An overview of HIV in the UK

Section One
An overview of HIV in the UK

Just under 1,000 children (aged under 18) were diagnosed HIV positive and accessing paediatric HIV health services in the UK in March 2007.[i] The vast majority of these children will have acquired HIV vertically (that is, have contracted HIV from their mothers during pregnancy, around the time of birth or through breast feeding).

An estimated 73,000 adults aged over 15 years were living with HIV in the UK in 2006; over 30 per cent of these did not know that they were infected.[ii] Some young people aged between 15 and 18 who are diagnosed during adolescence are counted in the adult statistics – and are therefore not in the children's data cited above – because they were diagnosed through adult sexual health services or data on them was obtained through ante natal services or surveillance of drug injecting.

However we know from combined data collection, covering both vertically and behaviourally infected young people, that there were 344 diagnosed young people between the ages of 15 and 18 accessing HIV care in the UK in 2006.[iii]

There were approximately 7,000 new cases of HIV diagnosed in 2006; an estimated 820 new diagnoses of HIV were amongst young adults (15–24 year olds). Where the source of infection was reported, 55 per cent of the young adults diagnosed with HIV in 2006 were infected through heterosexual contact.[iv]

What this information shows is that although HIV remains at relatively low prevalence in childhood, when the figures related to adult infection rates are analysed we can see that the rates for young people are significant in relation to the overall HIV positive population. The rates for this group have been consistently rising in recent years.

1.1 Issues faced by children and young people infected with HIV

Most children currently living with HIV in the UK have contracted HIV vertically. The development of antiretroviral therapy in the past 15–20 years has dramatically improved the outcomes for children living with HIV in the UK. It is now suggested that HIV be regarded as a treatable chronic disease.[v] Therefore, broadly speaking, most children living with HIV in the UK have a good health prognosis and most will survive their childhood and live well into adulthood.

The cohort of children living with HIV in the UK is gradually getting older, with a significant number now having reached adolescence. This group of young people who have grown up with HIV need specialist sexual health information, guidance and support in the areas of their personal relationships and entering adulthood. They require this support and information from a range of services.

1.2 Stigma

Fundamental to an understanding of how HIV impacts upon young people's lives is an understanding of the stigma an HIV diagnosis holds. It is this experience that young people consistently voice as the greatest challenge of living with HIV.

The stigma associated with a positive HIV diagnosis means that issues of confidentiality and the sharing of information are extremely important when considering the needs of young people living with HIV. Young people's fear of the discrimination they may experience if their HIV diagnosis becomes known about, particularly by their peers, is justified.

At a recent residential meeting held to consult with a group of HIV positive young people, the young people described the fear of rejection and the loss of control over their HIV diagnosis when considering whether to disclose their HIV status to a partner or friend. Consequently most had decided not to do so.[vi]

The secrecy that stigma enforces often leads to children and young people living isolated lives, with little opportunity to talk about their experience of living with HIV, ask questions and become well informed about HIV. As these children grow up and become young adults they have a continuing need for specialist knowledge and information concerning HIV, particularly relating to sexual health and managing relationships. Access to this specialist information is often lacking.

1.3 Service provision and support needs

Children and young people living with HIV describe wanting their lives normalised; they do not wish to be defined by their HIV status. They describe some specific needs: to be able to talk to someone they can trust about HIV; to talk to other young people who are also infected or closely affected; to have ease of access to information; and to get continuing information about HIV as they grow up.

Consequently we suggest there is a need for greater systematic understanding about young people living with HIV across generic services.

Most young people who have grown up living with HIV will have a clear understanding of whom they wish to disclose their HIV status to; many will not want their school or college to know their status. (See *Further information* Conway M (2005)).

1.4 Challenges during adolescence

Adolescence is the period of childhood which often presents challenges for many young people; involving negotiating boundaries and rights in order to make choices and decisions concerning their lives. It is also an important identity-forming period as transition from childhood to adulthood begins. For young people who have grown up with HIV the turbulence of adolescence is often compounded by specific issues.

- Many will have learnt the name of their diagnosis in early adolescence, as is current practice in paediatric HIV services, and may still be grappling with acceptance and understanding and experiencing emotional difficulties.

- Adherence to medication regimes is often particularly poor during adolescence as young people make active choices about not wanting to take medication or they find it difficult to maintain the strict regime as their lifestyles become less predictable.

- Peer relationships become increasingly important during this period; most HIV positive young people will feel unable to tell their friends their diagnosis for fear of stigma and rejection. Carrying this secret in friendships can be burdensome and emotionally difficult for young people.

- As this group of young people becomes sexually active they will need support when considering the need to disclose their HIV status to a sexual partner. This is an area where there is a need for careful explanations and sensitive understanding as there have been a small number of successful prosecutions of reckless transmission of HIV. HIV positive young people will need to be supported in their understanding of the need for condom use and also their need to consider carefully whether they are going to disclose their HIV status to their partner/potential partner. The area of criminal prosecution of HIV transmission is complex and ever changing, so it is important to seek current guidance on this area; this can be gained from the National AIDS Trust (see *Further information*).

- HIV positive young people beginning to engage in sexual activity may have significantly more complex ethical and legal dilemmas and emotional issues to grapple with than young people who are uninfected or undiagnosed.

Young people who become infected with HIV during adolescence will experience the above challenges within a condensed period. Most will be tested and treated in adult services and therefore not have the benefits of a child-centred approach to their health and healthcare needs.

2

Section Two
Looked after children and young people and sexual health

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Looked after children and young people and sexual health

In March 2007 there were just over 80,000 looked after children across the UK: 60,300 in England[vii], 14,060 in Scotland[viii], 4,640 in Wales[ix], and approximately 2,500 in Northern Ireland.[x]

Of these 3,300 were unaccompanied asylum seeking children.[xi] The number of children who are looked after and are either infected with or affected by HIV is not known, and it is not possible to estimate the numbers accurately.

2.1 The health of looked after children

There is wide-ranging evidence from research that children and young people who are looked after are often vulnerable in a number of areas. The aim here is not to stigmatise this particular group of young people further – clearly not all in this group suffer the extent of vulnerabilities described and not all looked after children engage in the high-risk behaviours of concern. Nonetheless it is important to highlight where there are current concerns relevant to this research.

It is widely suggested that the health of children in care is often very poor compared with that of their peers, with higher levels of substance misuse and significantly higher rates of teenage pregnancy than for the non-care population, and a much greater prevalence of mental health problems.[xii]

A point of particular importance is evidence that, because many looked after children experience highly disrupted educational and placement patterns, not only is their health and well-being history incomplete, they also miss out on health promotion and sexual health awareness work within schools.

Educational failure and exclusion is high among looked after children. This creates a loss of self-esteem, impairing emotional well-being, and poor emotional and psychological health that can lead to ill health, depression and often use of escape/coping mechanisms such as substance misuse.[xiii]

2.2 Young people and sexual health

Considering this vulnerability to risk-taking behaviour, missing periods of education, a corresponding lack of access to sexual health information and high rates of teenage pregnancy,[xiv] it is reasonable to suggest that looked after young people face a higher risk of contracting sexually transmitted infections (STIs), including HIV, than the wider youth population.

There is evidence that young people in general are at considerable risk of becoming infected with an STI, which would include a risk of contracting HIV. In 2006, two-thirds of genital chlamydia, 55 per cent of genital warts and 48 per cent of gonorrhoea infections diagnosed at GUM clinics were found in young people in the under-25 age group. Sexual health is described as being of particular concern in relation to young adults as, despite accounting for a small proportion of the UK population, young adults account for more than half of all STI diagnoses.[xv]

What is clear is that the rate of STIs in young people is on the rise, and this includes HIV transmission. As looked after children are more vulnerable to poor health and poor sexual health, all staff caring for them need awareness and guidance in policy and protocols to understand the impacts of a positive HIV diagnosis on the life of a young person, which includes their health needs and their psychosocial needs.

3

Section Three
Generic children’s policy overview

Section Three
Generic children's policy overview

This section describes some of the broader children's policy framework, highlighting aspects particularly relevant to the young people concerned in this research. Apart from the first document, which is HIV-specific guidance, there are limited references made to HIV.

Later sections refer to specific policy guidance relating to care provision.

3.1 Department of Health (2002) Children in Need and Blood-borne Viruses: HIV and hepatitis

This document focuses on meeting duties of care in relation to HIV and hepatitis. It is aimed at local authorities, the NHS, primary care trusts and other local providers. The guidance stipulates the following.

- The child's consent to disclosure of information regarding their blood-borne virus status should be sought whenever the child is of an age and understanding to provide it. Parental consent should be sought when the child is not capable of providing informed consent. (s5, para 15)

- Where the local authority has parental responsibility, the birth parents and any other person with parental responsibility should always be consulted, unless the local authority has decided that such a consultation would not be in the best interests of the child. Local authorities need to liaise closely with other agencies to ensure their procedures for maintaining confidentiality are appropriate. (s5, para 15)

- The local authority should provide full age-appropriate information in terms the recipient can understand, describing both the advantages and disadvantages of disclosing infection status. The guidance suggests that the need for disclosure should be non-directive and sensitive to the child and family's ethnic background, culture and language. (s5, para 16)

- If consent to disclosure is withheld, the decision of the child and parents should be followed wherever possible. If the child opposes this disclosure, the parents' consent should generally override the child's wishes only if the child is not of an age or understanding to consent. If the local authority officer is concerned that the welfare of the child and/or family is diminished because of their objection to disclosure, further discussions with the family may be appropriate. (s5, para 17)

- Generally the child's and/or family's wishes should only be overruled if any of the following apply:
    - the child is at risk of significant harm if disclosure is not made
    - there is a legal requirement for the information to be disclosed
    - public interest requires disclosure, for example in order to prevent others being put at serious risk. (s5, para 18)

3.2 Department for Education and Skills (2006) Information Sharing: Practitioners' Guide

This general guidance on information sharing states that a 16–17 year old or a child under the age of 16 who has 'the capacity to understand and make their own decisions' may consent to, or refuse, the sharing of information about them. Children aged 12+ can generally be assumed to have the capacity to understand and make decisions, and younger children may also have this capacity. The guidance suggests using the following questions to assess a child's capacity.

- Can the child understand the question being asked of them?

- Does the child have a reasonable understanding of: what information might be shared; the main reason(s) for sharing the information; and the implications of sharing/not sharing that information?

- Can the child or young person: appreciate and consider the alternative courses of action open to them; weigh up one aspect of the situation against another; express a clear personal view on the matter; be reasonably consistent in their view on the matter? (s4, para 18)

A refusal to consent to sharing information must be respected unless the child is suffering or likely to suffer significant harm without disclosure, or where there is 'sufficient public interest' to share the information (i.e. to protect others from harm or prevent crime and disorder).

3.3 UN Convention on the Rights of the Child (UNCRC)

Ratified by the UK in 1991, the UNCRC sets out the basic rights for children (defined as under 18 years).

The following articles are of interest.

- In all actions concerning the child, the best interests of the child should be primary consideration. (Article 3)

- A child who is capable of forming his or her own opinions should have the right to express those views freely in all matters affecting him/her. (Article 12)

- A child should not be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence. (Article 16)

- A mentally or physically disabled child should enjoy a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community. (Article 23)

- A child has the right to enjoy the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. (Article 24)

- A child who is placed by the appropriate authorities for the purposes of care, protection or treatment of his/her physical or mental health has the right to a periodic review of the treatment provided and other circumstances relevant to the placement. (Article 25)

3.4 Department of Health (2002) Promoting the Health of Looked After Children

This guidance for local authorities and healthcare bodies sets out the UNCRC articles and principles. It includes the legislative framework for promoting the health of looked after or accommodated children, the principles on which health services for looked after children should be based; and the roles and responsibilities of local authorities and healthcare bodies.

The key principles include:

- health assessments and plans should be based on promoting the current and future health of the child and not focused upon detecting ill-health

- the child or young person should be at the centre of the process and empowered (where appropriate) to take responsibility for their own health, with their wishes and feelings taken into account

- assessments and services should be sensitive to age, gender, disability, race, culture and language and should promote equality of access

- the child's informed consent to all healthcare and treatment should be sought and recorded in a way appropriate to the child's age and understanding

- obtaining consent from the child (or adult with parental responsiblity) to information sharing is a vital first principle to promoting the health of looked after children.

Local authorities must put in place arrangements to ensure that every child who is looked after or accommodated has:

- their health needs assessed
- a health plan setting out how these needs will be addressed
- the health plan reviewed, along with the care plan and in consultation with all relevant agencies and individuals.

The child's social worker is responsible for ensuring that this takes place. When carrying out the review, the social worker should take into account the child's wishes regarding what information will be shared at the review meeting.

Specific guidance on sexual health includes the following.

- Social workers and foster carers have a duty to ensure that looked after young people (including under-16s) and care leavers are encouraged to seek contraceptive and sexual health advice where they are, or are likely to be, sexually active. (s7, para 5)

- Social workers and foster carers should provide young people with the necessary support to resist pressure to have early or unwanted sex. (s7, para 6)

- Residential care workers and foster carers have a role in providing support to complement schools' drug education provision and in ensuring looked after children are aware of, and able to access, local services. (s7, para 13)

3.5 The Data Protection Act 1998

This provides the main legislative framework governing the way in which confidential information is used.

Disclosure is allowed where one of the following applies:

- appropriate consent has been given
- the information is required by statues or court order
- there is an overriding duty to the public (e.g. prevention, detection or prosecution of serious crime).

When information is disclosed it should be limited to the minimum necessary.

3.6 The Children Act 1989

The Children Act 1989 sets out local authorities' duties to safeguard and promote the welfare of children looked after or accommodated by them.

Before making any decision in relation to a looked after child or a child it is proposing to look after, a local authority should ascertain the wishes and feelings of the child and give them due consideration (subject to the child's age and understanding).
The authority should also consider the wishes and feelings of the child's parents or people with parental responsibility and those of any other relevant people.
(s 22, paras 4 and 5)

The Act also sets out arrangements for health assessments and healthcare provision for looked after or accommodated children. A registered medical practitioner must carry out the health assessment as soon as possible after making a placement; this health assessment is used to prepare a plan for the child's future healthcare.

3.7 The Children Act 2004

The Children Act 2004 aimed to strengthen the arrangements for multi-agency working to promote the well-being of all children. Section 10 provides the legislative framework for implementing aspects of the Every Child Matters programme. Local authorities and their partners are under a duty to cooperate with one another in order to promote the well-being of children and young people in terms of five key outcomes, that is for them to:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic well-being.

As case examples considered later demonstrate, following the guidance on sharing information between different agencies and the need to maintain tight control over the sharing of HIV status can present challenges.

3.8 The Disability Discrimination Acts 1995 and 2005

These Acts provide protection for disabled people in relation to access to goods, facilities and services (as well as other areas, including education and employment). The 2005 Act extended the disability discrimination legislation to cover people with HIV/AIDS from the point of diagnosis, and placed a general duty on the public sector to promote equality of opportunity for disabled people and eliminate discrimination.

3.9 National Service Framework for Children's and Maternity Services (2004)

This 10-year programme sets out 11 standards for health and social services for children, young people and pregnant women. The framework is made up of five core standards for services for all children and young people, followed by a number of specific standards for children, young people and parents with particular health needs. The following standards are particularly relevant to looked after children.

- The health and well-being of all children and young people is promoted and delivered through a coordinated programme of action, including prevention and early intervention (Standard 1). This includes ensuring information and services are offered to prevent risk-taking and promote healthy lifestyles in children and young people.

- All children who are ill have timely access to appropriate advice and services, which address their health, social, educational and emotional needs throughout the period of their illness (Standard 6).

Specific areas highlighted by the above are important foundations for developing local practice guidance on meeting the needs of looked after young people living with HIV:

- the promotion of looked after children's health, including sexual health awareness

- children's rights, particularly the right to be consulted in key decisions affecting their lives and also the right to give consent (when of sufficient age) to the sharing of their health information

- protection from discrimination regarding HIV status.

The following sections of this report consider the experiences of looked after children and young people who are HIV positive in different contexts. They cover:

- specific policies relating to the care context
- issues rasied by the children/young people
- issues raised by practitioners
- conclusions
- recommendations for practice.

The case examples describe the challenges to practice that practitioners have faced and the experiences of young people. They also describe the context and the need for organisations to consider carefully their need for policy, practice guidance and staff awareness-raising in this area.

All names have been changed to protect individuals' identities.

4

Section Four
HIV positive looked after children and social work: a case example

Section Four

HIV positive looked after children and social work: a case example

There are very few specialist HIV children and families social workers and they are only found in a small number of local authorities. It is therefore probable that a looked after child who is HIV positive will be solely allocated to a generic children and families social worker in a looked after children's team. Ideally the child will have access to a specialist HIV social worker for joint working, but often this is not the case.

The following case example highlights some of the challenges faced by an HIV positive looked after child and his social worker, who had no prior experience of working with children and young people who are HIV positive.

Case example one: Simon

Simon has been looked after by a local authority from the age of nine; he is now 16 and contracted HIV vertically. Like many looked after children he has faced significant challenges growing up. He has experienced the stigma of having a parent who is addicted to IV drug use and this has impacted upon him; he is also keenly aware of the stigma he faces living with HIV.

Simon is quite clear about whom he feels does and does not need to know about his HIV status. He feels it was necessary for his foster carers to be aware, but has not wanted his school, and now his college, to know. He has not been able to tell his friends about his HIV status, fearing their rejection.

> *'I wouldn't ever tell anyone about my HIV not at least until I'm an adult, they just wouldn't understand, they don't know about HIV.'*

Acceptance was identified as very important to Simon; he feels accepted for who he is by his social worker and the residential workers in the children's home where he currently lives. He describes this as meaningful to him and feels able to discuss issues relating to the impact of living with HIV with them.

> *'They are alright here, they accept me for who I am and just treat me normal – that's what I need.'*

But his fear of being rejected has meant he has chosen not to disclose his HIV status to girlfriends, and he has a fear of people learning that he has HIV and being rejected by them.

> *'I would really need to trust a girl to tell her I'm HIV, I couldn't trust her until I'm an adult. What if we're not together long – she could go and tell everyone and everyone would know; I'd rather wait until I'm older and I know I'm going to be with someone for a long time.'*

Simon's social worker described her experiences over the past two-and-a-half years, identifying some particular challenges and showing the ways in which she has been able to overcome these.

4.1 Awareness and understanding

The social worker identified that when she first began working on this case she had little awareness or understanding of the needs of children living with HIV and has had to learn whilst working with Simon. This has presented challenges as she has not always understood his concerns about other people knowing his HIV status and how best to support his emotional needs. In particular, as he entered adolescence and began to explore personal relationships, she felt less able to appreciate his needs.

There has also been a lack of knowledge and awareness across her social work department. The social worker has therefore had little access to information and guidance within her organisation and has had to access this from other agencies.

4.2 Difficulty establishing and maintaining placements

There have been problems in securing and maintaining foster placements. The problems began when Simon revealed his HIV status to prospective carers at the pre-placement-planning meeting. Simon had actively chosen to do this and on several occasions the offer of placement was then withdrawn.

When Simon was successfully placed with carers there was often insufficient understanding of the psychosocial impact on Simon of his HIV diagnosis and his corresponding emotional support needs. Carers had been competent at managing the practical health impacts of HIV and learning about medication, but had been less able to understand how Simon might show emotional and behavioural reactions through coming to terms with and accepting his own HIV diagnosis. The social worker felt foster carers had been hasty in ending placements without giving sufficient consideration to Simon's emotional and support needs. She considered that other looked after children remained in the placements despite exhibiting equal or increased levels of challenging behaviour.

4.3 Sharing of information

Problems were identified relating to information sharing. One example where this was difficult was Simon not wanting his school to be informed. Initially the social worker did not agree with this, feeling it was going against the recognised good practice of social workers sharing key information between relevant professionals. She described finding it challenging when asked direct questions by the school as to reasons for Simon's absences, or behavioural difficulties in school which could have been understood more if his HIV diagnosis had been known. Further on in her work with Simon she describes realising there was no need for his school to know and she gained greater understanding of Simon's need to control how far the information pertaining to his HIV status was shared. She also had to consider carefully how Simon's childcare reviews were managed. These needed to include separate fora for discussing issues related to Simon's HIV status, and Simon was consulted about whom he felt comfortable with attending these.

4.4 Conclusions

The social worker began her work with Simon with a lack of specialist knowledge and awareness, and received no specialist training. She gained knowledge and understanding through her long-term involvement, largely learning from Simon himself. There was a lack of such knowledge and awareness across the children's division, which meant there was little access to guidance and support in areas relating to HIV and care issues. The social worker therefore often made decisions without significant managerial supervision. Simon expressed how professionals' awareness and understanding of HIV were very important to him and enabled him to develop trusting, secure relationships.

The level of multi-professional involvement in the lives of looked after children presents challenges when considering the needs of a young person living with HIV. Control over sharing information about a young person's HIV status is extremely important in order to protect against stigma and discrimination, yet sharing of information is promoted as key to ensuring young people's welfare. This area can present ethical challenges between young people's right to control where their health information is shared (see section 3.1) and a professional's wish to share with key professionals information they perceive is in the best interests of the child or young person (see section 3.7). The learning from this case showed that the young person's wish to withhold consent to the wider sharing of information, for example with education, was fully appreciated by the social worker once she had become more experienced and had a greater understanding of the emotional and social impacts of HIV on young people.

HIV was identified to be the cause of a significant number of carers refusing to care for Simon, and also in placements breaking down, resulting in him spending more time at his family home. The fear of stigma was also significant. Simon's need to protect where the information relating to his HIV status was shared demonstrates that he was, and is, keenly aware of the stigma associated with HIV.

4.5 Recommendations

- All social workers should have training in basic awareness of HIV, to prepare them for an unforeseen referral of an HIV positive child or young person.

- It is important to consider appropriate social worker allocation to an HIV positive child or young person. Social workers on very short-term contracts are not appropriate. If possible, a long-term, consistent relationship needs to be established between the social worker and the young person. Reallocation to another social worker should be avoided.

- The social worker should establish early on a strong working relationship with a core group of professionals from the specialist health and voluntary sector.

- The core professionals involved should give guidance on who needs to be involved in the case at the outset, with specific attention to the young person's social and emotional needs.

- Measures on how to protect confidentiality need to be carefully planned, with potential scenarios considered, including crisis interventions. There needs to be careful planning of how information is received, recorded and shared.

- The young person's right to consent or decline the sharing of information concerning their HIV status must be central to decisions about who needs to know. This should include sharing information between local authority departments.

- Consideration of how care reviews will be conducted needs to happen immediately. This should include who will be involved and when discussion around HIV-related issues will take place. Again it is essential that the young person concerned is clear about whom they consent to having knowledge of their HIV status shared with.

- Professionals need to be aware of the issues young people face as they grow up with HIV and the support and ongoing information they will need as they grow up, begin sexual relationships and begin the transition to adulthood.

- The transition to the leaving care team may need to be taken at a much slower pace, to allow the young person to establish trust and confidence in the new social worker.

5

Section Five
Children’s homes: policy guidance and case example

Section Five
Children’s homes: policy guidance and case example

The National Minimum Standard and Regulations for Children’s Homes (DH 2002) sets out the care standards for children’s homes. The document makes specific reference to HIV/AIDS. It states that guidance for staff should cover HIV/AIDS awareness, confidentiality and infection control, and staff should receive training on the implications of HIV and AIDS when looking after children (Appendices 1 and 2).

Requirements under standard 12 of relevance include the following.

- The physical, emotional and health needs of each child are identified and appropriate action is taken to secure the services needed to meet them. Children are provided with guidance, advice and support on health and personal care issues appropriate to the needs and wishes of each child.
- Each child has a clear written health plan (within their placement plan) covering medical history and specific medical or other health interventions that may be required.
- A written record of all significant illnesses, accidents or injuries is kept during the child’s placement.
- Each child is provided with guidance, advice and support, appropriate to the child’s age, needs, culture and wishes, in relation to health and social issues, including alcohol and illegal substance misuse, smoking, solvents, sex and relationship education, HIV infection, hepatitis and sexually transmitted diseases, and protecting oneself from prejudice, bullying and abuse, both within and outside the home.
- The provider has a policy and written guidance, to be implemented in practice, regarding the promotion of the health of children in the home. This should cover a number of issues, specifically referring here to HIV and AIDS and other blood-borne diseases, as well as sexual health and substance misuse.
- Subject to age and understanding, children can decide whether they are accompanied by a staff member when seeing a health practitioner.
- Children with particular health needs or a disability are provided with appropriate support and help.
- Staff understand the needs of refugee children, asylum seekers and children from different racial and cultural backgrounds and seek specialist advice when necessary.

The following case example outlines the key issues raised in interviews with the staff of a small private children's home caring for a young person living with HIV who had been resident there nine months at the time of the interview. The case highlights the challenges faced by the organisation and how they were overcome.

Case example two: Ben

Ben grew up with HIV. He became a looked after child aged 10 and was told his HIV status when he was 12.

Ben had a number of foster placements before being accommodated in a small private children's home, following a failure to secure another foster placement for him. Ben had previous experiences in foster care where he felt his carers didn't understand why his behaviour was sometimes disruptive and he would become upset.

He was the only young person living at the children's home and was 15 when he arrived. Ben describes being happy at the children's home because *'everyone just treats me like normal – everyone's been alright with me'.*

Ben's previous experiences of being discriminated against because of his HIV status meant that simply being accepted was very important to him. He is keenly sensitive to stigma associated with an HIV diagnosis.

All members of residential staff were told before his arrival that he was HIV positive.

5.1 Awareness and understanding

When Ben arrived, staff had a half-day training session on basic HIV awareness and recognising the health needs of a person living with HIV; further training was provided by the local community nurse specialist. The local specialist HIV health team has given ongoing professional support.

The staff team experienced initial anxiety at managing a strict and quite complicated medication regime. The team did not feel sufficiently prepared with skills and knowledge and so, initially, Ben's medication was not properly monitored. Areas such as adherence were not sufficiently understood, and the staff did not know about contraindications of the HIV medication with other medication and/or illegal drugs and alcohol.

Following intense support from the local specialist health team, the staff now have good knowledge and understanding and feel competent at supporting the medication regime. However they felt that they should have had this knowledge and understanding prior to Ben's placement.

The issue of access to specialist health advice outside of normal working hours was also raised. On one occasion when Ben returned home intoxicated on a weekend night, the staff did not know whether it was safe for him to take his HIV medication and were unable to access this information from NHS Direct.

Staff fed back that they had responded to emotional needs around low self-esteem and lower life expectation that they had identified, by providing extensive one-to-one support. The staff were keen to stress the normalising of Ben, and to ensure that he was treated like any other young person. However, it was not clear whether staff had a sufficient understanding of the broad impacts of an HIV diagnosis to be able to respond to his emotional and social needs where they related to HIV.

5.2 Information sharing and confidentiality

All permanent staff at the children's home were informed of Ben's HIV status prior to his arrival, because staff on shift needed to administer securely stored medication. When staff were questioned on this issue, the response was clear: they felt there was a need for all members of staff to know, stressing that all staff were permanently employed at the children's home.

There was no confidentiality policy in the children's home prior to Ben's arrival, possibly because it was newly opened. The unit manager instigated the policy after Ben arrived.

There was an incident where Ben absconded and he was reported missing to the police. The missing person's form recorded that Ben took medication but did not disclose why. The police put staff under a lot of pressure to disclose his health condition, but staff refused, stating there was no need and it was Ben's confidential information. The staff were challenged in managing this incident, having no formal written guidance on confidentiality to support their decision.

5.3 Conclusions

Awareness and understanding

Initial lack of knowledge and understanding presented significant challenges for the staff team and impacted upon Ben's care and support, particularly in relation to supporting his adherence to a very strict medication regime.

The local specialist HIV health team's input has been very important, but this was needed much earlier, ideally before Ben took up the placement.

The training provided has focused on transmission issues and managing a medication regime. To date there has been no training around the psychosocial impacts of HIV on young people's lives and this has presented challenges to the staff team when emotional issues and social impacts have arisen. The emphasis has clearly been on normalisation, but this does not allow for the specific understanding of the psychosocial impacts of HIV on a young person.

Confidentiality and information sharing

There clearly was a strong commitment to maintaining the confidentiality of Ben's HIV status. However, the lack of formal written guidance outlining who did, and who didn't, need to know meant it was down to individual staff members to be sufficiently assertive and capable of resisting pressure to disclose.

The children's home had not considered that it was unnecessary for all staff in the home to know that Ben was HIV positive, and had not gained his consent for this information to be shared with all staff. The assumption had been made that it was necessary without fully exploring other options.

5.4 Recommendations

The following recommendations incorporate those suggested by the staff members.

- Basic HIV awareness training for all staff working with looked after children is needed.
- It should include a basic understanding of HIV and consideration of how HIV impacts upon the lives of children and young people.
- More detailed training will be needed for staff identified as needing to know a child or young person's HIV status. It should be provided as soon as possible following the referral of an HIV positive child or young person.
- Specialist training needs to cover: information on medication; the importance of adherence; risks of transmission; the impact of stigma and discrimination; addressing previous experiences of prejudice and discrimination; understanding emotional and social support needs; and understanding an HIV positive young person's specialist sexual health and relationships education needs.
- A formal written policy on confidentiality, which is easy to refer to, is necessary. It should state when to share information specifically referring to HIV, and when not to. It must include an explanation of a young person's right to give or refuse consent to their information being shared, and where it is acceptable to override their wishes in this area (see sections 3.1 and 3.2).
- There needs to be full discussion with the children's home manager at the point of referral, to decide which members of staff need to know the young person's HIV status. Agency or temporary members of staff should not be informed about the young person's HIV status. The recommendation here is to disclose the young person's HIV status to a small core group of staff, comprising the senior managers and, if felt beneficial, the young person's key worker. It is not necessary for the

whole staff team to be informed. Many young people spend very short periods in a children's home; it is unnecessary for an entire staff team, who may have limited contact with individual young people, to be made aware of their HIV status.

- Medication can be managed confidentially by placing it in weekly pillboxes, which don't identify the condition for which they are prescribed. The wider staff team can be informed more generally of a long-term health condition which impacts upon immunity. Young people should be supported in self-managing their medication regimes.

6

Section Six

Unaccompanied asylum seeking children: a case example

Section Six
Unaccompanied asylum seeking children: a case example

Of the looked after children in the UK, 3,300 are unaccompanied asylum seeking children, mostly over 16 years, and 31 per cent of all unaccompanied asylum seeking children are from African countries.[xvi] The Department of Health (2002) publication *Promoting the Health of Looked After Children* only specifically refers to HIV/AIDS under a section on asylum seeking and refugee children who may come into the care of the local authority. The document states that children coming from countries with a high risk of HIV infection may be orphaned due to HIV/AIDS or may be infected themselves (s10, para11).

The following case example demonstrates the level of sensitivity of understanding required by those being asked to care for young people living with HIV. It highlights how previous life experiences – particularly those relating to trauma, and the context of HIV in countries of origin – are very important areas of understanding when considering the needs of unaccompanied asylum seeking children who are diagnosed HIV positive. The emotional and psychological well-being of this particularly vulnerable group of young people are significant considerations.

Case example three: Maria

Maria arrived in the UK as an unaccompanied asylum seeking child aged 16. She had fled a war-torn country, witnessed the murder of her parents and many extremely traumatic events. She arrived in the UK alone, unable to speak English, having experienced a high degree of trauma, but also, at the age of 16, having lived independently.

She was initially placed with foster carers; Maria describes being very unhappy in the placement and feeling uncared for. When social workers refused to move her she left and was finally found a new placement. Two months into her new placement she was diagnosed HIV positive.

Maria was put under pressure by her doctor and social worker to disclose her HIV status to her foster carer. She didn’t want to do so but finally relented.

Maria was coping with her HIV diagnosis and her new arrival in the UK, but she was extremely socially isolated and felt very unhappy in her foster placement. The previous traumas experienced in her country of origin were also having an impact on her psychological and emotional well-being. Maria left her second placement as she was feeling stigmatised in the foster home after her foster carer learnt of her HIV status.

Following these two failed foster placements, Maria went to live in a supported housing project. A short time later Maria attempted suicide and was hospitalised. She was subsequently sectioned under the Mental Health Act.

> *'They [social services] told me they would be like my parents here and that they would look after me. They didn't look after me, I didn't get care from them – when I was in hospital after I tried to kill myself not one of them came to see me.'*

6.1 Awareness and understanding

Maria describes her foster carer's reaction to learning she was HIV positive as being very cold and she began by questioning her. Maria describes the foster carer showing no comfort towards her; she felt alienated, unsupported and stigmatised.

Maria soon left the placement of her own accord as she was experiencing unkind behaviour from the foster carer's daughter – she had her suspicions that the daughter had been told about her HIV status.

Maria's two experiences of foster care led her to refuse any further foster care placements; she describes feeling there was no real care for her.

Maria persuaded social services to place her in supported housing; they were initially unwilling to do so, but relented as she refused further foster placements. She was under no pressure to disclose her status, but after some time she built a relationship with a worker there and chose to disclose her HIV status during a period of feeling very low and being in need of some support.

Maria has had two different social workers allocated to her in the short time she has been in the country. Although she spoke about some helpful characteristics, key to her was having someone with some knowledge and understanding about HIV who could support her through the difficult process of coming to terms with her HIV diagnosis.

Maria had arrived from a country where HIV was prolific and led to serious illnesses and early death, largely due to a lack of availability of antiretrovirals. She needed a social worker who was aware of these issues and could help her to understand HIV in the UK context.

6.2 Sharing information

After her diagnosis Maria, describes being put under a lot of pressure by her social worker and doctor to tell her new foster carer her HIV status; she is clear that she did not want to do so.

She finally relented to the pressure to disclose her status during a visit to the hospital for her HIV-related care, and her doctor informed the foster carer. The disclosure was unplanned.

There was significant sharing of Maria's HIV status with other professionals and agencies when her mental health became of concern. Throughout this experience Maria was not empowered to decide to whom she wanted this information shared.

6.3 Social and emotional needs

Maria had experienced serious trauma and was also trying to come to terms with her HIV diagnosis.

She therefore suffered from significant emotional and psychological distress. This distress increased over time, during which she had two failed foster care placements and was allocated to two different social workers.

She was finally placed in supported housing, but after a short while her emotional distress increased and she attempted suicide and was hospitalised. Critically, Maria described how she felt completely alone and that no one from social services visited her in hospital following her suicide attempt: her allocated social worker was away from work at the time.

Maria now has access to a specialist support organisation where she has peer and one-to-one support. This has been invaluable to her.

6.4 Conclusions

Maria's case involved tragic experiences in her country of origin. This is not unusual for those people living with HIV who come from countries where there is a high prevalence of HIV causing huge numbers of deaths and inflicting long periods of serious illness upon large numbers of people. This is often compounded with the experience of protracted violent civil conflicts where many women have been infected with HIV as a consequence of rape. Young people from such countries often arrive having witnessed and been the victims of extreme violence and having suffered significant losses.

Young people who are coping with an HIV diagnosis in these circumstances may also be dealing with loss, bereavement and abuse, as well as having to adjust to a new country and culture, cope with uncertainties around immigration status, and learn a new language. The challenges these issues present are immense and complex.

Maria's case highlights that there can be serious emotional and social impacts resulting from the compounding of these experiences, which will result in significant, emotional needs. The extent of these psychological and emotional needs may take some time to emerge following diagnosis.

The lack of control over information sharing, and the further rejection that Maria experienced from a foster carer who did not show the warmth and care she needed when she learnt about her HIV status, only served to inflict further damage on an already highly vulnerable young woman. There were very serious implications for the safety and well-being of this young woman.

6.5 Recommendations, including those suggested by Maria

- All social workers working with unaccompanied asylum seeking children should be trained in basic HIV awareness.

- Problems can occur when health histories are taken with unaccompanied asylum seeking children. There are often missing pieces of history and so it is not possible to give a correct assessment of health risks. Guidance on testing for blood-borne viruses in looked after children who are UASC's should be consulted. (See *Further information* Le Provost, M and Williams, A (2008))

- As with all looked after children with HIV, careful consideration should be given to the allocation of a social worker to a child or young person with HIV when they are newly arrived in the UK, having no family or other support to turn to. The social worker needs to have sufficient experience, be knowledgeable about HIV, and be willing and able to provide significant emotional support. She or he will hold confidential information and will need to be a consistent key support and source of guidance and information for the young person.

- Young people arriving alone may have more experience of being responsible for themselves and have greater capacities in looking after themselves than other young people of their age in the UK; they should be consulted and listened to when considering how to look after them.

- Young people must be afforded their rights to give or withhold consent to the sharing of their HIV status (see section 3.1). They must not be put under pressure to disclose, for example to carers, when it is clear they do not wish to do so.

7

Section Seven
Foster care: policy guidance and case example

Section Seven
Foster care: policy guidance and case example

Foster carers have clear duties to meet the broad health and well-being needs of the children they look after. These duties are outlined in the following regulations.

7.1 The Fostering Services Regulations 2002

These provide the statutory framework for the provision of fostering services. Section 15 places a duty on fostering service providers to promote the health and development of children placed with foster parents. The service must ensure that children:

- are registered with a GP
- have access to required medical, dental, nursing, psychological and psychiatric advice, treatment and other services
- receive individual support, aids and equipment required as a result of health needs or a disability
- receive guidance, support and advice on health, personal care and health promotion issues appropriate to their needs and wishes.

Section 17 states that the fostering service provider must ensure the foster carer is given up-to-date information about a child in their care, in particular regarding the state of the child's health and health needs and arrangements for giving consent to the child's medical or dental examination or treatment.

7.2 National Minimum Standards for Fostering Services (DH 2002)

These cover the promotion of the health and development of looked after children. Standard 12 states:

'The fostering service ensures that it provides foster care services which help each child or young person in foster care to receive healthcare which meets her/his needs for physical, emotional and social development, together with information and training appropriate to her/his age and understanding to enable informed participation in decisions about her/his health needs.' (s12, para 1)

Specific requirements include the following.

- The fostering service should be informed about local health services, including specialist services, and take this into account when identifying a suitable foster carer for a child. No placement should be made that prevents a child from continuing to receive required specialist healthcare services.
- A foster carer should be provided with a full description of the child's health needs before the placement begins – or, where information is not available, as soon as possible after placement – along with details of arrangements for giving consent for medical examinations and treatment.
- Foster carers should be provided with a written health record for each child in their care, updated during the placement. The record moves with the child, and he or she should have access to, and be supported to understand, the record according to his or her age and understanding.
- Every carer must have basic training in health and hygiene and first aid.
- The fostering service must make clear to carers their role in promoting the health of a child in their care. Responsibilities include: registering the child with a doctor and dentist; accompanying the child to health appointments; helping the child to access required services; giving attention to health issues in everyday care including, for example, diet and hygiene; and acting as an advocate for the child.
- The fostering service should maintain good links with health agencies and support the carer in securing appropriate services for the child.
- The fostering service must require carers to provide information about children's health needs for planning and reviews.

Even though there is no specific mention of HIV, these broad health promotion and protection duties will apply to the healthcare provision for a young person living with HIV.

However, there are ethical challenges raised by some of the guidance, particularly around the duty to provide foster carers with full health information on a young person's health needs before the placement begins or as soon as possible afterwards.

This issue can present practice dilemmas as young people may not wish to disclose their HIV status to their carers. Some may only be being looked after for a short time and would not feel able to trust a temporary carer with this information. Yet foster carers may assert they need to have this information in order to meet their duties in supporting the healthcare needs of the young people they care for. Also, a child or young person may be diagnosed whilst in placement and may not wish to share this information with the foster carer.

Again it is important for practitioners to revert to the legislation and guidance that affords children the right to consent, or withhold consent, to sharing information on their HIV status (see section 3.1). Issues such as maturity and competence would need to be assessed in this instance, to determine the young person's capacity to manage his or her healthcare needs related to HIV without the direct input of the foster carer.

Foster carers are currently able to opt out of caring for children with HIV during the selection process. The matching considerations/specific needs question on the F1 Fostering and Adoption assessment form (which guides the assessment criteria used to approve foster carers) asks whether a carer is prepared to care for a child with various characteristics. ‘AIDS or HIV’ is listed under a child’s existing medical condition, along with Down’s syndrome, autistic spectrum disorder, cerebral palsy, foetal alcohol syndrome and hepatitis B or C. It is considered the assessing social worker’s role to explore this issue with a prospective foster carer. However, the following case example highlights the potential damaging effects of a foster carer being unaware of HIV and the resulting discrimination against a young person in her care.

Case example four: Samira

Samira arrived aged 15 as an unaccompanied asylum seeker from Uganda. She was diagnosed HIV positive in pregnancy, not long after her arrival in the UK.

She was placed in foster care. Initially her carer was not told about her HIV status, but she found out later whilst accompanying Samira on a hospital visit.

After learning of Samira’s diagnosis the foster carer told all her family, gave her separate cutlery and plates and placed anti-bacterial wipes in the toilet, which were not there before. Samira began to feel she was being treated very differently from everyone else.

This treatment led to Samira feeling lonely and isolated from the rest of the family. She became increasingly unhappy and spent as much time as she could away from the home with her young baby.

Finally Samira left the placement of her own accord with her young baby and bags and arrived at a specialist HIV project. She refused any further foster placements. She went to stay with a friend for a while and was eventually housed in bed and breakfast accommodation.

7.3 Awareness and understanding

The foster carer clearly did not have basic understanding of HIV, as her behaviour demonstrated completely unfounded fears of transmission of HIV.

The foster carer also lacked an awareness of the need to maintain strict confidentiality of HIV status. This would not be uncommon among foster carers, as most will not have received appropriate HIV training.

Samira's health team referred her to an HIV specialist support project that began to advocate for her. The project contacted the unaccompanied minor's team that had placed her with the foster carer, but the team showed little understanding about her needs and did not address the concerns about the placement.

The specialist HIV support project did attempt to engage the foster carer in awareness-raising work to support her understanding of HIV but the foster carer was not willing to participate. The project concluded that this was not simply a case of the foster carer needing information, as this was being offered, but that the carer was unwilling to engage in work to raise her awareness and understanding of HIV.

7.4 Information sharing

The unplanned disclosure of HIV to Samira's foster carer led to Samira losing control of the information regarding her HIV status and resulted in further serious breaches of her confidentiality.

The foster carer's subsequent negative reaction to Samira being HIV positive meant that she had an extremely difficult experience of foster care.

This experience highlights the need for all onward disclosures of HIV to be carefully planned, with essential information and guidance provided immediately.

7.5 Conclusions

Lack of knowledge and awareness were key problems in this case; all attempts to engage the foster carer in training and awareness-raising were unsuccessful. The foster carer was unwilling to equip herself with better understanding about HIV.

The foster carer's reaction, on learning that Samira was HIV positive, discriminated against and further stigmatised Samira. This, combined with the breaching of her confidentiality, resulted in the placement breaking down.

The opt-out option in the selection of foster carers, by identifying HIV status as a matching consideration in the assessment process, may allow discrimination based on HIV status to go undetected in the selection process.

Other chronic treatable diseases of childhood such as diabetes or sickle cell are not listed. This singling out of HIV has the potential to allow discriminatory attitudes towards HIV held by foster carers to persist.

Under the Disability Discrimination Act 2005, HIV positive people are provided with protection from discrimination from the point of diagnosis, thus recognising the ongoing impacts of stigma faced by those living with HIV.

It may not be known at the outset that a child placed with a carer is HIV positive, or a young person may choose not to share this information. A young person may also become infected during adolescence. The risk that a foster carer holds prejudices in this area and could then reject a young person who is diagnosed HIV positive whilst in his or her care is not acceptable.

Samira's experience highlights that discrimination based on HIV status persists, and illustrates the harm it can cause. It led to the breakdown of her placement and had a significant emotional impact on Samira. She felt stigmatised and rejected because she was HIV positive.

Foster carer anxiety around HIV was cited throughout this research as an issue. Health and social services professionals working with looked after children raised lack of awareness about HIV among foster carers as a significant problem.

7.6 Recommendations

- HIV needs to be presented as a potential issue for any child being placed into foster care. This allows services to be prepared for specialist practice issues and, importantly, to allow for discriminatory attitudes to be screened in foster carers prior to their registration.

- Increasing HIV awareness and understanding in foster carers' basic training is likely to increase their willingness to take on caring for a child or young person diagnosed HIV positive, and also reduce the risk of discriminatory attitudes and behaviour being expressed by carers of children or young people diagnosed HIV positive whilst in their care. This discrimination is, on the whole, likely to be underpinned by misunderstandings about HIV.

- Foster carer services should make all foster carers aware of current guidance on HIV and AIDS. The Fostering Network has produced specialist guidance for foster carers *HIV and AIDS: Information for foster carers*.[xvii] The guidance covers a range of areas aimed to equip carers with an understanding of transmission issues; issues carers may be working with when caring for children; the psychosocial impact of an HIV diagnosis; and also definitions of HIV and AIDS.

- Samira, Simon and Maria's cases illustrate the difficulty in placing an HIV-infected child in foster care, and the impact of a diagnosis during this time. The difficulties raised here can only be resolved through local authority policy guidance on placements of HIV positive children, with clearly identified practice solutions. The case examples highlight the need for greater foster carer awareness of HIV and how it can impact upon children and young people.

7.7 Good practice example

A fostering service based in Lothian in Edinburgh saw a high level of HIV infection through intravenous drug use in the 1980s.

The approach taken by the Lothian Department of Social Work was to make no distinction between children infected with HIV and those affected due to a parent being HIV positive.[xviii]

The key difference in this service is that all carers, including respite carers, foster carers and prospective adoptive parents, were given regular information and training about HIV and AIDS. The department made it clear that all foster families were required to understand and accept that any child placed with them could be infected with HIV. If they were not able to do this they were not considered able to continue caring in that locality: it was explained that it is rarely known whether a child is HIV positive.

This practice was developed in the early 1990s, when antiretroviral therapies were new and much less effective than the types of drugs available today. The health impacts of HIV were therefore significant and the need for respite care due to a parent's hospitalisation, for example, would have been more relevant. However, there are features of the practice experience that remain relevant because of the prevailing social impact of HIV.

This service provides an example of integrating an understanding and awareness of HIV into a mainstream fostering service. It demonstrates a stance taken whereby there is no tolerance of discrimination by foster carers refusing to care for an HIV positive child; it makes clear that all carers must be prepared to care for a child with HIV.

Although this service was responding to a locally specific context, the principles on which it is based could easily be applied more widely.

8

Section Eight
Identifying and managing risks related to HIV and looked after children: case examples

Section Eight
Identifying and managing risks related to HIV and looked after children: case examples

The vulnerability of looked after children with regard to poor health and well-being has already been documented (see Section 2). Risk-taking behaviour is often a significant problem for looked after young people; and managing risk has been a common theme raised through this research as a key challenge faced by professionals, particularly as it is very difficult to find guidance which is sufficiently specific to the circumstances that HIV presents. This is particularly so in the context of current concerns around keeping all children safe, criminal prosecution and culpability.

This section considers the key features of cases that highlight the experiences of young people who have engaged in high-risk behaviour, some having very unstable placement histories and all having few stable attachments to professional or familial relationships. The cases reflect some young people who have grown up living with HIV who have become looked after children following an unstable home life, the others have become infected with HIV during adolescence as looked after children. The section includes descriptions of case examples followed by the practice challenges they presented.

Case example five: Lee

Lee had unsafe sex with his girlfriend to whom he had not disclosed his HIV status.

He was concerned about the event and shared it with staff at his children's home; they in turn reported it to the social services' duty social work team. The duty team did not know how to respond and referred it to their manager. A child protection response was undertaken regarding the girl. There was a panic response, immediate action was considered necessary, strategy meetings were held between different managers within the children's service and a significant number of social services staff then learnt about Lee's HIV status.

The girl's parents learnt what had happened and began proceedings to prosecute for reckless transmission of HIV under Section 20 of the Offences Against the Person's Act 1861, although there was no evidence that transmission of HIV had taken place.

Lee was referred to a specialist legal advisor. After this meeting he panicked and went straight to the police station and handed himself in.

The police did not know what to charge him with and so charged him with sexual assault, although the girl was the same age as him and at this stage was still untested.

The girl concerned was later tested by an adult sexual health service. She tested negative for HIV. Her parents and the police dropped all charges.

8.1 Practice challenges – Lee

The children's home staff had no access to policy and practice guidance to support their decision-making process around sharing confidential information. They therefore made a referral to the duty social work team. This was received in the context of child protection and responded to as such.

This incident highlighted the widespread lack of awareness and understanding of HIV among statutory services and, in this instance, the police. Misunderstandings about risks meant that management decisions within children's services were based on a panic response. Equally, the police were ill-equipped with awareness and understanding and quickly criminalised the behaviour of the young man, even though no criminal offence had taken place and there was no knowledge that HIV had been transmitted.

There was a very fast move to criminalise the activity; the police were willing to enforce this criminalisation, even before it was known whether HIV had been transmitted. This is of concern as, to date, a small number of adults have been successfully prosecuted. (See *Further information*, the National AIDS Trust.)

For Lee this experience was frightening, intimidating and stigmatising and his confidentiality rights were completely breached. The impact of this was felt for a considerable time. Many people learnt about his HIV status, he began receiving abusive phone calls, and was forced to cut himself off from a circle of friends.

The incident could have been managed within the core multidisciplinary professional group already caring for Lee. A planned approach could have been taken to address the issue of the risk that transmission of HIV may have taken place. The need to test the girl could have been assessed by the paediatric specialist HIV team and, if necessary, they would have undertaken the testing.

This planned approach would have prevented a huge breach in Lee's confidentiality and protected him from the highly stigmatising experiences and wide ramifications that sharing his HIV information led to.

Case example six: Luke

Luke's case highlights difficulties that professionals experience when faced with the possibility that a looked after young person who is HIV positive and leading a chaotic lifestyle and engaging in a wide range of risk taking-activities, is thought to be having sexual relations with another young person without using condoms.

Luke had contracted HIV through vertical transmission and so had grown up HIV positive. He became a looked after child at a young age, having suffered sexual abuse. He began to exhibit challenging behaviour and progressed to misusing drugs and alcohol. Luke's behaviour led to him having multiple placements, mostly in children's homes across the country.

Luke would frequently abscond from his placements; there were concerns that older men were sexually exploiting him during these periods of absence.

Whilst staying at a children's home, he began a relationship with a young girl outside of the children's home. The staff at the children's home became concerned that he was having sexual relations with her, and that he may not be using a condom. Both children were under the legal age of consent at the time.

The children's home staff tried to engage Luke in conversations about his sexual activity to assess whether he was using condoms, but he would not engage with them and simply denied anything was going on.

8.2 Practice challenges – Luke

The social worker involved in this case described the challenges the case presented, firstly acknowledging the difficulty in safeguarding the health and well-being of an HIV positive young person whose lifestyle already presented significant risks.

The second challenge was the difficulty in engaging Luke in addressing the issue of risk that he could transmit HIV to another individual, as he refused to admit to having sex with the girl.

The concerns within the social work department heightened and it began to consider its duty to inform the girl in question that she may have been put at risk of contracting HIV. The department felt that sharing this information would involve breaching Luke's confidentiality rights, as his HIV status would have been shared.

A series of strategy meetings were held on this issue, and legal and professional expertise and guidance sought, yet no clear guidance on the right to breach confidentiality in such circumstances was available.

The outcome was that Luke was placed in secure custody for factors unrelated to this issue. The concerns over whether the local authority had a professional duty or moral obligation to inform the girl of the possible risk that she may have contracted HIV were not resolved.

The key practice challenge identified from this experience was that of managing risks related to transmission of HIV with looked after young people who have chaotic lifestyles and engage in high-risk behaviour, and the lack of policy and practice guidance in this area.

Case example seven: Nathan

Nathan became looked after at age 11; he was subject to a full care order. He had been engaging in general anti social behaviour and low-level criminal activity from a young age. As a teenager Nathan presented ever more challenging behaviour and he became increasingly difficult to care for. This led to a series of placements in different areas across the country, mainly in children's homes, with periods in secure accommodation and custody in youth offending institutes.

Nathan began a pattern of absconding from placements. During these periods of absence his carers and social workers had little or no knowledge of his whereabouts.

His placement history was therefore highly erratic and unstable and he had few stable relationships with his carers or other professionals.

At 16 he was under the leaving care team, and supported by social services with accommodation. A worker saw him on one occasion in extremely poor health, he had lesions on his face, and she immediately escorted him to hospital. Nathan was promptly diagnosed HIV positive and given a diagnosis of AIDS, defining him as asymptomatic with a form of skin cancer.

Nathan spent time in hospital being treated and was put onto an HIV drug therapy regime. Following his discharge he was accommodated in a flat and a support package geared towards supporting independent living for care leavers was put in place.

Nathan died of an AIDS defining illness within six months, following an emergency admittance to hospital shortly before his 17th Birthday.

8.3 Practice challenges – Nathan

A senior manager involved with this case shared some of the key practice challenges and the areas of learning the service has identified.

Very little was known about Nathan between the ages of 14 and 16; he frequently absconded from his placements and little was known about where he went or whom he associated with. The level of risk these absences of care and protection presented to his well-being were not fully appreciated; absconding from placements is, to an extent, normalised among many looked after children whose behaviour is very challenging. These young people can be disengaged from professional relationships. Attempts to stabilise Nathan through periods of secure accommodation and custody were only successful during the time of detention and his previous absconding behaviour resumed upon his release.

The absences from care meant that any deterioration in his health and any indications of health problems were missed.

Nathan's HIV consultant estimated his time of infection, based on disease manifestation, to have been around the age of 12–13. There is no understanding of how Nathan may have become infected; he never trusted anyone enough to discuss possibilities. The lack of a trusted supporting relationship with a professional in this young person's life was significant both to this lack of knowledge about him and to the ability of the service to provide him with sufficient post-diagnosis care and support.

After his HIV diagnosis there was insufficient understanding of Nathan's significant care and support needs related to HIV, particularly the importance of ensuring that he adhered to a strict drug therapy regime, which is essential in suppressing the HIV virus and maintaining good health. Nathan was seen by an adult HIV consultant and admitted to an adult ward when hospitalised. Upon his discharge he was supported in the community but without sufficient consideration being given to the specialist understanding required of how a young person with a chaotic history such as his would need to be intensively supported in coming to terms with an HIV diagnosis and, crucially, need intensive support with adhering to an antiretroviral therapy regime.

Specialist paediatric HIV health professionals have experience of managing the very important drug therapy regimes for children and are highly experienced in working with adolescents who adhere poorly to their medication. Their services are frequently flexible and child-focused, including significant support strategies and community interventions. They are therefore best equipped to provide the intensive support needed.

For a young person having already experienced an AIDS-defining illness, it would be essential that they adhere to their antiretroviral therapy regime. In this instance it seems as though this young man, who was clearly disengaged from those who provided and were responsible for his care, was treated more like an adult than a child when it came to managing his healthcare.

8.4 Conclusions

These cases highlight the significant challenges presented when HIV features in the lives of young people who are already chaotic, taking risks with their health and well-being and are disengaged from the professionals involved in caring for them.

They also illustrate how HIV often instigates a panic response. A lack of understanding about HIV can lead to breaching confidentiality of HIV status, and this can lead to highly stigmatising impacts. In Lee's case, an HIV positive young person having one incident of potentially unsafe sex was reacted to as a critical incident and potentially criminal activity.

It is clear that challenges are compounded by concerns over risk of transmission of HIV to another young person. Organisations do not have clear policies on information sharing in place to support their decisions on whether they have a duty to breach the confidentiality rights of a young person when it is considered possible they have put someone else at risk of contracting HIV.

It is important to consider that there have been several successful prosecutions of reckless transmission of HIV. Therefore the issue of whether there is a need to inform another person who is thought likely to have been exposed to a risk of contracting HIV has to be carefully explored. The expertise of the specialist HIV paediatric health team must be sought, as well as guidance and advice from the National AIDS Trust (see *Further information*).

The issue of risk of transmission and also of health support illustrate why it is essential to establish a strong, effective working relationship with the nearest paediatric specialist HIV health professionals' team, even if the young person in question is over 16.

The risk of contracting HIV was not considered within the safeguarding concerns around a looked after young person whose behaviour was known to be presenting considerable risks of harm to his health and well-being. Little was known about what happened to him during periods of absences of care; risks to his sexual health needed to be considered within the framework of concerns about his health and wellbeing.

8.5 Recommendations

- It is important that such young people are afforded their status as children; the paediatric HIV health professionals, in partnership with adult HIV specialists, are best placed to support their needs.

- Organisations need clear policy on maintaining confidentiality and practice guidance based on a young person's right to consent to the sharing of their information related to HIV status, but also outlining where the refusal to give consent may be overruled (see sections 3.1 and 3.2).

- Due regard to the confidentiality rights of a young person must be maintained even in the event of a perceived critical incident. Where at all possible, young people should be consulted when there is a request to share information about their HIV status. Every effort should be made not to instigate a panic response, and to plan responses in collaboration with the multi-professional team already working with the young person. It is essential to work closely with the speciaist paediatric HIV health team. Duty social work teams and adult sexual health teams should not be accessed unless there is an urgent need for out-of-hours action.

- There is a serious need for greater awareness of HIV across the wider children sector; all key staff involved in work with looked after children need HIV awareness training.

9

Section Nine
HIV diagnosis during adolescence: a case example

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HIV diagnosis during adolescence: a case example

This section offers a detailed case example of two young people who had had close involvement with social services during their childhood and became infected with HIV during adolescence. It considers the wider social impacts of their HIV diagnosis, which were largely defined by extensive breaches to their confidentiality and a considerable lack of knowledge and awareness among professionals and in the wider community.

Interviews were undertaken with the two young people and several professionals in an isolated region of the British Isles; a community that is subject to a different legal system to England.

Professionals in this locality expressed considerable concern about being identified in this document. The cases exposed a high degree of stigma in the local community associated with HIV. The community was in shock that HIV had 'arrived there'.

The case example also highlights that no region of the UK, no matter how isolated, is in a position to state that it has no need to be concerned about young people living with HIV.

Although at the time of the interviews neither of the two young people concerned was a looked after child, they both had extensive previous experience of social services involvement which included accommodating them for periods.

Case example eight: Sarah and David

Sarah is now 17 years old; she had a lot of difficulties in her family home which led to her being referred to CAMHS at the age of nine. She ran away from home at 14 and spent a brief time in a secure children's home. She left there and from then on led an unstable lifestyle, withdrawing from mainstream education and living with friends. Sarah was allocated to social workers, but they had little success in engaging her in services. No formal care arrangements were made for her, although she was accommodated by social workers in supported lodgings for brief periods.

When she was 15 she was living independently with her boyfriend David, nearly two years older than her.

David is now 18. He described having social services involved in his care from a young age and spent approximately three years in children's homes and a secure unit. He described suffering a lot of depression during that time.

In his early teens, David began using a lot of alcohol initially and then illicit drugs. By the time he reached 16, he was living in a flat on his own. Social services were not supporting him at this time.

Sarah and David were friends with a group of young people in their locality who shared similar experiences. They were disengaged from their families, had spent time in children's homes, and had unstable lifestyles, involving high-risk behaviour, substance misuse, anti-social behaviour and low-level criminal activity.

David visited his GP when he was 17 regarding a skin rash. He had some routine blood tests and the GP told him he thought he could be HIV positive. This was a Friday evening and his doctor told him to go to the hospital GUM clinic for a second set of tests to confirm his diagnosis and to take his girlfriend with him to be tested.

David was diagnosed HIV positive at the age of 17. Sarah was diagnosed HIV positive at the age of 15.

David attempted suicide one month after his HIV diagnosis, he describes feeling he couldn't cope and he wasn't receiving any support. He was hospitalised and after he was discharged he felt he had to leave the locality where he lived to escape the community where so many people had learnt about his HIV status. He and Sarah both left for several months, however their relationship broke down and they returned, when they returned David describes how clear it was to him that their HIV status was common knowledge.

In the months following their HIV diagnoses, both Sarah and David engaged in further risk-taking activities involving drug use and criminal activity, their lives became increasingly chaotic and their relationship broke down. They both ended up convicted of drug-related offences, and at the time of interview Sarah was detained in prison, and David had recently been released from prison.

9.1 Awareness and understanding

The young couple had no access to support, information or guidance at the point of their diagnosis. They were not advised on how to manage the information, and were not advised against onward disclosure of their status to others.

No specialist support was made available to them for a number of months, although Sarah was accessing emotional support from CAMHS. Although there was a specialist HIV agency in their vicinity, they were not referred there for some months. Sarah and David described being in a state of shock and denial.

For this particular community there was clearly widespread ignorance about HIV. This ignorance extended to many of the professionals working directly with these young people.

Sarah experienced stigma and discrimination both at her education provision, when other students learnt about her HIV status, and during a brief stay at one of the supported hostels where she was accommodated by children's services. When, seeking support, she told the warden her HIV status, she was asked to leave the accommodation the following day.

The prison officers interviewed were frank in sharing their initial ignorance about HIV. They had had no formal training, and they described having to learn about HIV along the way with much of their understanding having been gained from Sarah. The small staff team of permanent officers enabled a good system of support, with one officer making particular efforts to improve her knowledge and understanding of HIV and be supportive to Sarah. This relationship has been significant to Sarah. The need for someone to talk to, to build trust with and receive emotional support from has been highlighted by all the young people throughout this research.

9.2 Confidentiality and information sharing

Sarah told members of her family and some friends after her diagnosis. She now regrets doing this, as there have been many ramifications as these people then openly shared her information with others. She feels she was completely ill-equipped to manage her diagnosis, as at the time she was given no guidance on onward disclosure. Without the necessary guidance and support, Sarah at 15 was unaware of the importance of careful consideration and planned disclosure of her HIV diagnosis.

Upon arriving in prison, Sarah disclosed her HIV status, as was explicitly asked for it in a health questionnaire. The prison officers interviewed stated that they already knew her status: it seemed most people in the small community knew. As such, Sarah was not in a position to keep her health information confidential. For both Sarah and David, being in a small community led to their status becoming public knowledge.

The lack of control over this information has led to some very stigmatising experiences for Sarah and David, including an article published in a local newspaper detailing that two local teenagers had become infected with HIV. Sarah now regrets having told anyone as she completely lost control over where the information was shared.

David felt he has had no control over so many people learning of his HIV diagnosis, partly due to Sarah's initial disclosures. He is also convinced that services shared this information widely between themselves, stating that all services knew he was HIV positive, including children's services, education, probation and the police.

In one incident, David referred himself onto a Prince's Trust Team Programme, run by the Youth Service. On this occasion, after choosing to disclose his HIV status, the information was dealt with appropriately.

As part of David's experience on the Team programme, all the young people were to go for leg waxing at the local college. During the lunch break, the girl who had waxed David's legs was approached by another student and told that David had HIV. She told her college tutor, who contacted the youth worker and said they should have been told. The youth worker defended his position on there being no need to disclose. The head of the college became involved and finally the Education Authority was contacted. They supported the youth worker's decision not to disclose the information to the college, as there was no risk of transmission. Nonetheless David's confidentiality was widely breached during this incident, leading to a significant experience of active discrimination.

The youth worker described how difficult it was to stand his ground during such an incident, as there was no guidance and no policy to which he could refer to support his decision.

This demonstrates the importance of clear policies on confidentiality and protocols on information sharing.

Recently David was arrested. A police officer commented to another officer to watch out as he had HIV and David had a cut hand at the time.

This feeling that everyone knows his HIV status has caused David significant paranoia. He feels very anxious about going out anywhere as he has experienced a lot of abuse and harassment on the streets; he described having been beaten up on several occasions.

9.3 Managing risk

Sarah's life after her diagnosis became increasingly chaotic; she was injecting heroin, she did not keep appointments made with social workers, and she did not attend her alternative education programme. Sarah was emotionally and psychologically very vulnerable, and at risk of harm from her IV drug use. Additionally, Sarah had not at this time received any specialist support around her HIV diagnosis.

Sarah was soon convicted of a drug trafficking offence and given a prison sentence. The different legal context (from mainland UK) in which she lives allowed her to be admitted to an adult female wing of a prison at the age of 16.

David was also convicted of drug-related offences and given a prison sentence.

The prison officers and social workers interviewed expressed anxiety about the high level of risk-taking behaviour in a group of young people in the community, a group that both David and Sarah were part of. This insular group was known by the services to be engaging in substance misuse and thought to have sexual relations with each other.

The social workers identified insufficient attention having been paid to prevention and were very concerned about needle sharing. To date these risk factors, which include the possible onward transmission of HIV, have still not been addressed.

9.4 Conclusions

These cases offer a stark example of the implications of uncontrolled information sharing. Social workers describe these two young people as having HIV in the context of a huge amount of other challenges, which were the cause of concern for their safety and well-being. The social workers described both young people as being very chaotic and difficult to engage with.

Despite the social workers' description, David and Sarah were both extremely keen to talk about their experiences and articulate where they felt they had not received the support they needed.

In general, the social workers were challenged by trying to work with teenagers who were disengaged from social institutions. Both young people had previous experiences of involvement with social services which had not been positive for them; they are now extremely vulnerable, and in need of extensive support.

Both cases identify the significant need for early intervention and support to be provided to newly diagnosed young people. This support and guidance could have prevented a lot of the wider ramifications and stigmatising experiences that resulted from the lack of control over who learnt about their HIV diagnoses.

These case examples illustrate how a lack of preparation in policy and practice guidance on confidentiality and information sharing, and insufficient staff knowledge and awareness, make it very difficult for organisations to have planned, considered responses and respond well to unplanned events. In such a context, HIV tends to invoke a panic response. This in turn leads to breaches in confidentiality that can never be repaired.

David's experience of a Prince's Trust Team programme highlights how an appropriate response to the holding of information about an individual's HIV status does not protect the individual from previous breaches of confidentiality, which continue to have ramifications. Here again the need for clear guidance and written protocols on sharing information about HIV with other services was identified.

Different professionals expressed a very clear desire to normalise the young people concerned. Clearly this came from a desire to ensure equality – that these young people should not be treated differently because they are HIV positive.

However, this focus on normalisation, as highlighted in previous case examples, can lead to insufficient appreciation of the stigma surrounding an HIV diagnosis and how this impacts socially, psychologically and emotionally. As such, young people diagnosed HIV positive will have specialist support needs around managing the impacts of their diagnosis.

Perhaps the most significant issues these cases highlight are, firstly, that HIV is an issue for every community to consider no matter how isolated and secondly, that wider societal ignorance around HIV remains a very big problem which inevitably leads to extensive discrimination of the HIV positive person.

9.5 Recommendations

These recommendations include those offered by the young people and the practitioners interviewed.

- Professionals working with young people need basic awareness training on HIV.
- Those working directly with HIV positive young people need additional awareness of the social and emotional impacts of HIV, an understanding of stigma and discrimination, and a clear understanding of the need to maintain confidentiality of HIV status. Information on these topics needs to be available in addition to general information on HIV.
- There is an urgent need to raise public awareness about HIV, to address the widespread ignorance that persists and leads to active discrimination and, in these cases, was the cause of significant emotional and psychological distress for these young people.
- Organisations need very clear guidance related to managing HIV, addressing how information concerning HIV status is received, recorded and shared. This practice guidance needs to cover how to manage interagency working in social work practice relating to HIV. Young people's right to consent to the sharing of their HIV status has been well documented throughout this document; see sections 3.1 and 3.2.

David identified some key areas that would have helped him come to terms with his HIV diagnosis and what he has learnt from his experience of HIV:

> *'When I was diagnosed I needed someone to talk to, a point of contact who could provide me with ongoing guidance, give me support and information when I needed it – like a key worker.'*
>
> *'Don't tell your friends to begin with, maybe think about who to tell later on.'*

(This advice reflects the usual practice within specialist HIV healthcare. At the point of diagnosis/disclosure a child/young person would be advised to keep the information to themselves, and they would be directed to particular support where possible.)

> *'Confidentiality needs to be tightened up; services should not be sharing information amongst themselves.'*

David feels extremely isolated and alone and feels he would benefit from being able to talk with other HIV positive young people:

> *'I would really like to meet with another young person who is HIV positive, even just to talk to them and find out how they cope, how they deal with living with HIV.'*

10

Section Ten
Conclusions and recommendations

Section Ten
Conclusions and recommendations

This research aimed to discover what kinds of care experiences looked after children who are HIV positive have had, how their HIV status has affected their care and the interventions of different professionals in their lives. It also sought to understand the kinds of challenges professionals have faced, what they had learned from these challenges and how equipped their organisations have been to support them, in areas such as training and awareness raising of staff, practice guidance and policy.

This group of children and young people is small, but this research has shown that these cases can present complex issues for practitioners. Ignorance and misunderstandings around HIV can lead to some very difficult and harmful experiences for children and young people. It is hoped that the learning that can be gained from this small group of young people will be widely useful, that it will help organisations and professionals to be better prepared and equipped to meet the needs of an HIV positive child or young person, and that some of their difficult experiences are not repeated.

10.1 Conclusions

Awareness and understanding about HIV

Broadly speaking, a widespread lack of awareness and understanding about HIV underpinned much of the findings in this research. It was the area identified as a problem by all professionals interviewed, causing challenges in meeting the needs of looked after children. These challenges presented across the young person's care career: from initially finding suitable placements, to foster carer's refusals to take on HIV positive looked after children, through to maintaining placements and placements remaining intact when a young person became diagnosed HIV positive.

The lack of awareness and understanding of HIV was highlighted in the areas of understanding transmission, and fears around transmission were significant. Practitioners felt ill-equipped, lacking sufficient knowledge and understanding to support the many psychosocial issues that HIV infected children and young people can experience.

Basic HIV training became available to many professionals working directly with HIV positive young people, but this only covered transmission, with a focus on health protection. There is sexual health training for all professionals working with looked after children, but HIV is not covered as a specialist area.

Professionals consulted here had not received training on understanding the social and emotional impacts of HIV, understanding stigma and discrimination and appreciating confidentiality issues. These are all defining features of caring for a child or young person living with HIV.

The professionals described that their primary source of learning about HIV came from the child or young person, most having been unaware at the beginning of their involvement. This is not best practice. HIV positive looked after children need specific support, guidance and information from those caring for them, and these needs will change as they grow up.

Professionals caring for these children need to be properly equipped to offer this support: understanding how HIV impacts upon a young person beginning to form personal relationships; how their HIV status affects their peer relationships and their particular emotional needs; and understanding the issues to consider when a young person begins to think about disclosing his or her HIV status to friends or partners.

The young people interviewed described a need for the people who look after them – their social workers, residential workers, foster carers – to be knowledgeable about HIV. They expressed that it is important they feel able to talk to them about HIV, that they should be both a source of information and emotional support.

Widespread misinformation about HIV clearly leads to those living with HIV experiencing stigma and discrimination. This was found to be particularly harmful when the misinformation was held by the carer, leading to highly stigmatising experiences for the young person being looked after and, in several cases, to placement breakdown.

Placements which broke down due to foster carer ignorance and lack of understanding of HIV left the young people concerned unwilling to go to another foster placement, to protect themselves from experiencing further rejection.

There was a lack of awareness and understanding of how important it is for HIV positive children and young people on antiretroviral therapy regimes to adhere to their drug regimes. Nathan’s case is a sobering reminder that HIV remains a terminal illness. If people do not adhere to their antiretroviral therapy regime, clearly their life can be at risk. This highlights the importance of establishing a close working partnership with the specialist HIV health team caring for the child or young person.

Confidentiality and information sharing

Professionals have highlighted significant practice challenges, relating to the lack of available guidance within their organisations on sharing information regarding HIV.

This generally falls into two areas. The first is managing ethical dilemmas around concerns relating to high-risk behaviour (for example when it is thought an HIV positive young person is having sex with another person and may not be using condoms). This research has shown how challenging it has been for professionals to make these ethical and moral decisions on whether to share information about an individual's HIV status. There is a need for organisations to have clear policy and practice guidance on this.

The second area identified is how information about a person's HIV status is frequently shared unnecessarily and that there is often insufficient regard to the individual's confidentiality rights. Local authorities apply the concept of 'need to know' when considering what information should be shared with other professionals and outside agencies. However, this concept can be open to wide interpretation. Most importantly, applying the need-to-know concept to the sharing of information does not eliminate the need to gain consent from the young person prior to disclosure. The assumption is often made that other professionals and agencies need to know without sufficient questioning of whether this is so and frequently without obtaining the young person's consent. Young people frequently raised the concern that information was shared between services and professionals without regard to their confidentiality and without them being consulted to give their consent. In one case a young person's social worker was keenly aware of the need for the young person to give his consent to the sharing of his HIV status, but other professionals involved in this young person's care did not work with the same ethics, and wider sharing of his HIV status took place.

Young people also described being put under pressure to disclose their HIV status to their carers and agreeing to this under duress. This resulted in placement breakdown, largely due to the lack of understanding shown by the carer.

Clearly the right to give consent must be meaningful and it therefore includes the right to refuse consent.

What is clear is that the ramifications of sharing information for these children and young people are significant. This is particularly the case in smaller, isolated communities where the distinction between professional information and wider public information is even more difficult to maintain. It can lead to young people feeling stigmatised, isolated and alone, and subject them to further risks of rejection, discrimination and abuse.

Stigma and discrimination

Underpinning all of the themes highlighted here is the continued prevalence of stigma and discrimination which can still be seen to be formed from widespread ignorance surrounding HIV and misinformation around fears of transmission.

Some of the young people had experienced stigma and discrimination from carers. Their fear of stigma continues to underpin their experience of living with HIV and creates the climate of fear and secrecy in which many live. All the young people were concerned about people in their wider communities finding out about their HIV status, for fear of rejection and, in some cases, fear of abuse.

This experience of living with a highly stigmatised illness, largely in secret, often leads to particular emotional and social impacts. All the young people here described needing someone they could trust to talk to who was well informed and knowledgeable about HIV; they also talked about the need to build up trust with this person. It is clear this relationship needs to be consistent.

It is important to recognise that there are examples of excellent support and guidance provided by foster carers caring for looked after children who are HIV positive. The carers found to be particularly skilled are those who are mature, experienced, with very good awareness and understanding about HIV, a willingness to learn about HIV and a readiness to engage with health professionals to ensure the best possible support for these looked after children.

Managing risk

This research has shown that managing risk has been a challenge to many of the professionals involved in these cases. This has included risk of harm to self as well as risk of transmission of HIV to another person.

The risk of contracting HIV during adolescence when young people are engaging in high-risk behaviour has been highlighted and must be recognised.

This research has also revealed that HIV often causes a panic response, and incidents are unnecessarily responded to as a crisis. Significant anxiety has been expressed concerning HIV positive young people having sexual relationships where there is concern that they are not using condoms.

It is also clear that non-medical professionals are not always sufficiently aware of the continued threat to life that HIV presents and the significant risks presented to a child or young person's health if they do not adhere to their antiretroviral therapy regime.

10.2 Recommendations

Training and awareness raising

All those working with looked after children should undertake basic awareness training.

Professionals who need to be more prepared for working with HIV positive looked after children should have training in the following areas: information on HIV medication; the impact of stigma and discrimination; understanding emotional and social support needs; awareness of the specialist sexual health and relationships educational needs of HIV positive young people; awareness of the issues a young person faces as they grow up with HIV; maintaining the confidentiality of the young person's HIV status; and understanding the serious ramifications of breaches in confidentiality.

Policy and guidance on sharing information about HIV

A local authority or voluntary organisation looking after a child has a duty of confidence in respect to the affairs of that child. Because of the sensitive nature of HIV diagnosis it is necessary for local authorities and others to plan carefully how information pertaining to a child or young person's HIV status is received, recorded and shared. Measures on how to protect confidentiality need to be carefully planned, with potential scenarios, including crisis interventions, considered and planned for.

Wider services involved in working with looked after children have no need to know a child or young person's HIV status when they become involved with them. Discussion around HIV needs to be conducted in a separate forum when undertaking childcare reviews. It is essential that the young person concerned is consulted in this planning and is clear on whom they consent to having their HIV status shared with.

It is not necessary for all staff members of a children's home to be informed of a young person's HIV status. This information should be contained within the management team. Managers of children's homes should ensure they have clear written guidance on maintaining the confidentiality of young people's HIV status, which needs to be specific, outlining with whom information can be shared.

Complex ethical dilemmas presented when duties to protect different young people's well-being are in conflict need careful unravelling. Explicit guidance on when it is necessary to breach confidentiality needs to be worked out and included in practice guidance on information sharing. This can include a statement about the need to protect other young people from contracting HIV when it is known they are engaging in high-risk behaviours with an HIV positive person. However, this must address the need for such a scenario to be managed sensitively, maintaining due regard for the HIV positive young person's right to consent to the sharing of their information, and must be undertaken in close consultation with the specialist paediatric HIV health team.

Children and young people must be afforded their rights to control where information concerning their HIV status is shared. Organisations need to ensure this right is defined in specific practice guidance.

If a young person does not wish to share their HIV status with a foster carer then consideration should be given to the young person's age, maturity and ability to manage their healthcare needs relating to HIV. It should not be assumed necessary for a foster carer to know a young person's HIV status; a young person should not be put under pressure to disclose when they have expressed a wish not to do so.

Specialist HIV paediatric healthcare provision

Specialist HIV paediatric healthcare provision has the experience and capacity to provide intensive support to children and young people living with HIV. This level of support is not typically provided by adult healthcare services. Young people who are diagnosed HIV positive during adolescence should be referred to specialist HIV paediatric clinics where at all possible. Looked after HIV positive young people in particular are likely to need increased levels of support in coming to terms with their diagnosis, and when necessary, beginning an antiretroviral therapy regime. The paediatric team will liaise with the adult health team and plan for a gradual transition to adult healthcare.

Partnerships

It is very important to work closely with the specialist paediatric HIV health team in managing the cases of looked after children living with HIV. It is important to establish early on a strong working relationship with a small core group of professionals from health and specialist voluntary sector organisations (where possible). Guidance on who needs to be involved in the case should to be sought at the outset, with specific attention given to the young person's social and emotional needs. This multidisciplinary forum should be used for decision making when necessary, controlling the extent to which the child or young person's HIV status is shared with other professionals.

Recognising and responding to risk

The risk of contracting HIV during adolescence when young people are engaging in high-risk behaviour needs to be recognised. This risk must be considered when a child or young person's health assessment is carried out. The risk of contracting HIV must be incorporated into sexual health awareness education undertaken with young people and other harm reduction strategies such as addressing IV drug use.

The risk that HIV may have been transmitted on from the HIV positive looked after child or young person to another individual must be managed with a planned approach. The specialist HIV paediatric health team should be consulted and a planned approach taken to assessing whether there is a risk of transmission of HIV and how testing should be approached.

The National AIDS Trust should be consulted for guidance if there is concern that transmission has taken place in the light of concerns around prosecutions of reckless transmission of HIV.

Professional and practice considerations

Where possible, an HIV positive child or young person needs long-term allocation to one social work professional. It is not appropriate to allocate to a short-term member of staff. The young people consulted in this research consistently defined trust and the ability to confide in a care professional as being very important. The transition to the leaving care team may need to be taken at a much slower pace, to allow the trust and confidence in the new social worker to be established.

There are clear reasons to question the inclusion of HIV as a matching consideration, which potential foster carers are able to opt out of during their assessment.

First, a child's HIV status may not be known; they may become diagnosed later in their childhood, or may contract HIV during adolescence. The young person may choose not to disclose their HIV status to their foster carer. These children and young people run the risk of being discriminated against by a carer who had opted out of caring for an HIV positive child in their matching considerations on their assessment.

Second, the Disability Discrimination Act 2005 clearly protects all people living with HIV from discrimination from the point of diagnosis. No other treatable chronic diseases of childhood are listed as matching considerations in the fostering assessment form. It is not acceptable for HIV to be singled out.

All carers need to be willing to care for an HIV positive child or young person, and must be equipped to respond appropriately to a young person in their care who could be diagnosed HIV positive during their placement. HIV positive children and young people must not be put at risk of being stigmatised and discriminated against by those who have been given the role of caring for them as looked after children.

Foster carers can provide an excellent supportive role caring for HIV positive children and young people; they need to be equipped to do this with access to specialist training and information. The Fostering Network's publication *HIV and AIDS: Information for foster carers* (2007) should be made available for all foster carers.

References

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[xviii] O'Hara, G 'Caring for children and families infected and affected by HIV/AIDS: A social work perspective', in Batty, Daphne (ed) (1993) *HIV Infection and Children in Need.* London: BAAF.

Further Information

AVERT presents accumulative data of both national and global HIV figures.
Visit www.avert.org.uk

Health Protection Agency collects quarterly data on the number of people living with HIV. They can provide, on request, more specific information on regional data.
Visit www.hpa.org.uk/cdr

The National Study of HIV in Pregnancy and Childhood (NSHPC) collects data through confidential obstetric and paediatric reporting systems and produces a quarterly newsletter with regularly updated tables. For more information and to receive the newsletter email: nshpc@ich.ucl.ac.uk

Children and Young People HIV Network works nationally to bring together organisations concerned with children, young people and HIV/AIDS. The Network aims to be an effective voice for children and young people living with and affected by HIV in policy and practice development, and to challenge stigma and discrimination.

Children and Young People HIV Network
National Children's Bureau
8 Wakley Street
London
EC1V 7QE
Tel: 020 7843 1911 | Email: hiv@ncb.org.uk | www.ncb.org.uk/hiv

Conway M (2005) 'HIV in Schools: Good practice guide to supporting children infected or affected by HIV'. London: National Children's Bureau.

This guide provides practical information and suggestions on ways of supporting children and young people living with HIV in schools.

The Children's HIV Association (CHIVA) is an association of professionals committed to providing excellence in the care of children infected or affected by HIV and their families. Membership includes practitioners from nursing, GU Medicine, paediatrics, community child health, child development, psychology, social work, dieticians, pharmacists and support services.

For more information visit www.bhiva.org/chiva

Children with AIDS Charity (CWAC) was set up to help the youngest of those infected with or affected by HIV and AIDS to maintain a good quality of life. It is a national UK charity with the aim of working towards a future without prejudice for these children and their families.

Children with AIDS Charity
Calvert House
5 Calvert Avenue
E2 7JP

Tel: 020 7247 9115 | Email: info@cwac.org | www.cwac.org

National AIDS Trust (NAT) is the UK's leading independent policy and campaigning voice on HIV and AIDS. NAT develops policies and campaigns to halt the spread of HIV and AIDS, and improve the quality of life of people affected by HIV, both in the UK and internationally. See website for updated information on criminal prosecutions for HIV transmission.

NAT
New City Cloisters
196 Old Street
London
EC1V 9FR
Tel: 020 7814 6767 | Email: info@nat.org.uk | www.nat.org.uk

Terrence Higgins Trust (THT) is the leading HIV and AIDS charity in the UK and the largest in Europe. It has national and regional offices across the UK, offering a range of services and information.

THT (National Office)
314-320 Gray's Inn Road
London
WC1X 8DP
Tel: 020 7812 1600 | Email: info@tht.org.uk | www.tht.org.uk

Le Prevost, M and Williams, A (2008) Guidelines for the testing of looked after children who are at risk of a blood-borne infection: A joint social services and health document. London: BAAF.

Offers multi-agency guidance on considering the need for looked after children to be tested for blood-borne infections, covering procedures on how to identify, assess, test and refer children at risk of blood-borne infections.

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